

Patient and Client Council

Your voice in health and social care

Our lived experience of waiting for healthcare

People in Northern Ireland share their story

March 2018

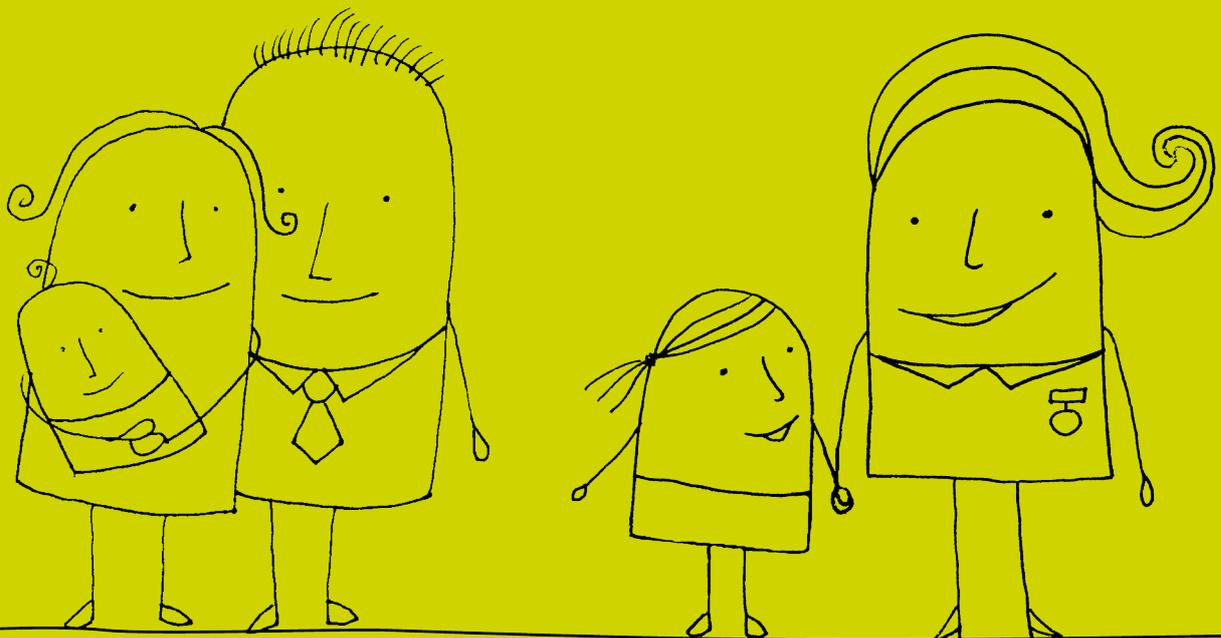
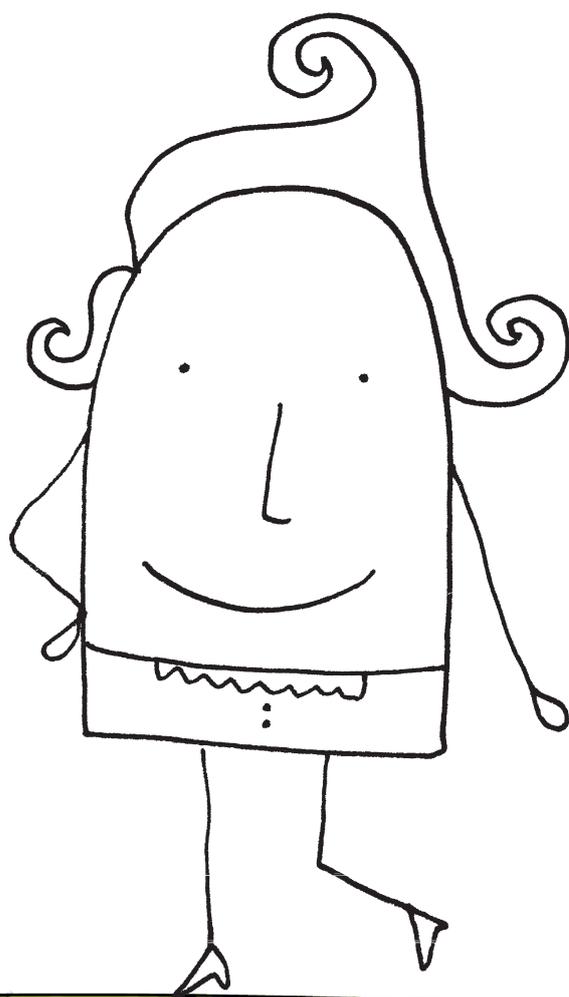


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Executive Summary

At the time of publishing this report most recent waiting time statistics reveal that none of the ministerial waiting time targets are currently being achieved in Northern Ireland.

- ▶ 73,380 patients are waiting more than a year for a first consultant-led appointment;
- ▶ 13,176 patients are waiting more than a year for either an inpatient or day case admission;
- ▶ 18,697 patients are waiting more than 6 months for a diagnostic test;
- ▶ 38% of patients are not receiving their first treatment for cancer within the 62 day target set for urgent GP referrals for suspect cancer;
- ▶ more than 8% of cancer patients are not receiving their first definitive treatment within 31 days of decision to treat; and,
- ▶ approximately 25% of patients with an urgent breast cancer referral are not being seen within the 14 day target.

However stark, these statistics tell us little about the lived experience of being on a waiting list for treatment and care. It is important that this experience is not overlooked in the conversation. People accept that there are many reasons why they may have to wait for treatment. It is when waiting is prolonged and starts to adversely affect their physical and mental health that they become anxious and frustrated.

Complaints regarding waiting times have consistently featured as one of the top areas of complaint for the Patient and Client Council (PCC) Complaints Support Service across the last three years. Complaints relating to waiting times refer to many different specialties with a small number of complaints in each. The exception to this is orthopaedics, which is consistently identified as a major area of concern.

We gathered information from approximately 700 individuals nearly half of whom said their health had deteriorated while being on a waiting list. Nearly a third of those participants highlighting worsening pain as a key issue. The negative impact on mental health was also explicitly described. However, the impact of being on a waiting list was wider than the impact on their health. Patients also referred to the wider impact on their social lives and their financial wellbeing.

Our findings add to the growing body of evidence that indicates long waits for treatment and care can impact on the physical, emotional, social and financial wellbeing of patients and their family and carers.

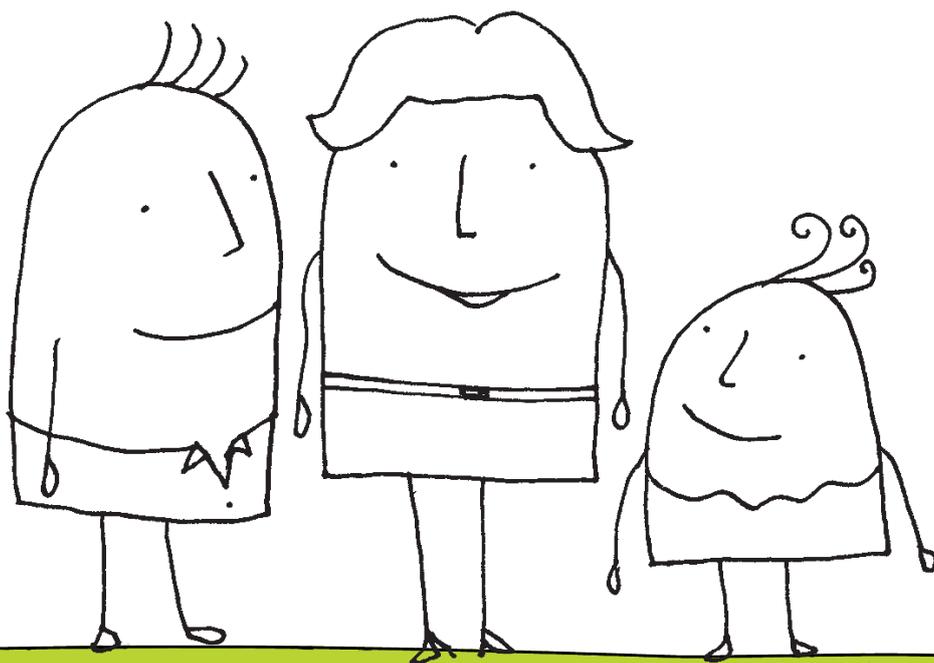
People we spoke to also raised concerns about the inequity in access to healthcare that is particularly evident between those who are able to access private healthcare and those who are not. The waste of healthcare resources, e.g. medication and the added burden on GP services while people remained on waiting lists, was also cited as a concern to participants.

While over 70% of participants said they were generally aware of the current situation with hospital waiting lists in Northern Ireland, nearly half felt it had not been made clear how long they personally would be expected to wait when they first received a referral. Furthermore, nearly 80% of people said they were not followed up while they were on the waiting list to determine whether they still needed

the appointment. About 60% of people believed that they had not been made aware about what would happen if they could not or did not attend an appointment.

The majority of participants stated that they would have liked to receive more information. They felt better communication would help in managing expectations; that more accurate information is needed to make decisions on whether to pay for private healthcare; that acknowledging referrals and providing status updates could ease anxiety and provide reassurance to people that they had not been forgotten. Participants felt that the current approach of information provision via letters was inefficient and outdated and that processes needed to be implemented which supported two-way communication. This was closely linked with the call for information to demonstrate accountability i.e. that it is not sufficient for people to be told where they are on a waiting list, rather they need to be provided with information as to what measures were being taken to manage the waiting list and reduce their waiting time. Most commonly people called for information to be accessible and accurate, as participants felt that current estimations of waiting times which are provided to patients are not realistic and result in people putting their lives on hold.

It is important to note that the people who participated were supportive of healthcare staff and appreciative of the care when they received it. They recognised that the current waiting times were a result of a system that was not working well and not the fault of individual healthcare staff.



1.0 Introduction

1.1 Current context - Northern Ireland waiting time statistics

The Department of Health in Northern Ireland provides quarterly waiting time information for the following four areas:

1. a first outpatient appointment;
2. admission for inpatient/day case treatment;
3. a diagnostic service; and
4. cancer services.

Each statistical release presents information on waiting times and reports on the performance of the Health and Social Care (HSC) Trusts against the ministerial waiting time target in Northern Ireland. The most recent publications highlight that none of the ministerial waiting time targets are currently being met.^{1,3,5,7}

1.1.1 First outpatient appointment

Ministerial Target

"By March 2018, 50% of patients should wait no longer than 9 weeks for a first outpatient appointment, with no patient waiting longer than 52 weeks."

At 30th September 2017 there were 272,656 patients waiting for a first Consultant-led appointment in Northern Ireland. 74.6% (203,401) of patients were waiting more than 9 weeks and 26.9% (73,380) of patients were waiting more than 52 weeks.¹

For the same period five years ago the target was: 'at least 50% of patients should wait no longer than nine weeks for a first outpatient appointment, and no patient should wait longer than 21 weeks.'

At 30th September 2012 there were 107,874 patients waiting for a first outpatient appointment. 30.6% (33,035) were waiting more than nine weeks and 5.2% were waiting more than 21 weeks.²

1.1.2 Admission for inpatient/day case treatment

Ministerial Target

"By March 2018, 55% of patients should wait no longer than 13 weeks for inpatient/day case treatment, with no patient waiting longer than 52 weeks."

At 30th September 2017, there were a total of 75,240 patients waiting to be admitted to hospitals in Northern Ireland. Almost one third (32.4%, 24,364) were waiting for an inpatient admission, with the

remaining 67.6% (50,876) waiting for a day case admission. 62.5% (47,009) of patients were waiting more than 13 weeks and 17.5% (13,176) of patients were waiting more than 52 weeks.³

For the same period five years ago the target was: 'at least 50% of patients should wait no longer than 13 weeks, and no patient should wait longer than 36 weeks, for inpatient admission.'

At 30th September 2012 there were 50,720 patients waiting to be admitted to hospitals in Northern Ireland. Almost one third (31.7%, 16,098) were waiting for an inpatient admission, with the other 68.3% (34,622) waiting for day case admission. 40.1% (20,341) were waiting more than 13 weeks for inpatient treatment and 2,029 patients were waiting longer than 36 weeks.⁴

1.1.3 Diagnostic test

Ministerial Target

"By March 2018, 75% of patients should wait no longer than 9 weeks for a diagnostic test, with no patient waiting longer than 26 weeks."

"From April 2017, all urgent diagnostic tests should be reported on within two days of the test being undertaken."

At 30th September 2017 there were 112,521 patients waiting for a diagnostic test. 49.2% (55,340) of patients were waiting more than 9 weeks and 16.6% (18,697) of patients were waiting more than 26 weeks. Of the 49,780 urgent diagnostic tests reported on during quarter ending September 2017, 86.3% (42,974) were reported on within two days.⁵

For the same period five years ago the target was: 'no patient should wait longer than nine weeks for a diagnostic test (13 weeks for a day case endoscopy), and all urgent diagnostic tests should be reported on within 2 days of the test being undertaken.'

At 30th September 2012 there were 63,042 patients waiting for a diagnostic service at HSC Trusts in Northern Ireland. 19.4% (12,233) were waiting longer than 9/13 weeks and over 87.0% of all urgent diagnostic tests were reported on within two days.⁶

1.1.4 Cancer waiting times

Ministerial Target

"From April 2017:

(i) at least 95% of patients should begin their first treatment for cancer within 62 days following an urgent GP referral for suspected cancer

(ii) at least 98% of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat

(iii) all urgent breast cancer referrals should be seen within 14 days."

In September 2017, 38% of patients did not receive their first treatment for cancer within the 62 day target set for urgent GP referrals for suspect cancer. More than 8% of cancer patients did not receive their first definitive treatment within 31 days of decision to treat; and, approximately 25% of patients with an urgent breast cancer referral were not seen within the 14 day target.⁷

For the same period five years ago the target was: '95% of patients should begin their first treatment for cancer within 62 days following an urgent GP referral for suspect cancer.'

In September 2012, 80.0% of patients were treated within 62 days following an urgent GP referral for suspect cancer, 97.8% were treated within 31 days of a decision to treat being taken and 100% of patients given an urgent referral for suspect breast cancer were seen within 14 days.⁸

1.2 Comparison to statistics for the rest of the UK

The Northern Ireland waiting time crisis has been subject to media scrutiny over the last several months with various speculations as to why targets are not being met. One chief economist described Northern Ireland's hospital waiting list figures as "shocking, unnecessary, unacceptable and the worst in the UK". He also pointed out that "one in seven of the entire population of Northern Ireland are on an outpatient waiting list, compared to England where it is one in 14"⁹ Four of Northern Ireland's five health Trusts are among the 10 worst emergency department performers in the UK.¹⁰

Direct comparison between waiting time statistics for Northern Ireland and the rest of the UK is not readily available because in the rest of the UK, waiting time data are no longer collected on separate outpatient and inpatient waits as is still the case in Northern Ireland. Other regions have moved to Referral to Treatment (RTT) time targets, which measure the total time the patient has to wait from referral to treatment. In Northern Ireland, the Department of Health do not measure complete patient journey time from GP referral to start of treatment. Once a referral for a first outpatient appointment has been made, the waiting time 'clock' starts and then stops once they have been seen by a Consultant / specialist. A separate waiting time 'clock' starts if the patient requires inpatient treatment on either a hospital admission or day case basis, or if they require a diagnostic test.

1.3 Contributing factors to the waiting list crisis

There are four key elements which appear to contribute to this crisis

- ▶ Increasing demand due to changing population
- ▶ Under investment and/or failure to transform service delivery
- ▶ Workforce planning
- ▶ Increasing gap between capacity and demand for elective services.

1.3.1 Increasing demand due to the changing population

The population in Northern Ireland is growing with people living longer and the number of those requiring specialist health services increasing.¹¹ Mid-year estimates for 2016 indicated there were 1.82million people living in Northern Ireland and population projections predict this will rise to 1.947million by 2025 which is an increase of 5.2%.¹² This rise in population will be mainly due to the rise

in the proportion of older people, many of whom have complex co-morbidities. It has been estimated that between 2015-2025 the number of people aged 65+ will increase by 77,000 to 369,000, a rise of 26%. Long waiting times can in part be attributed to the increasing demand for services that are not configured to meet the needs of the population.¹³

1.3.2 Under investment and/or failure to transform service delivery

In one media report Dr Anne Carson, Chair of the British Medical Association, Northern Ireland Consultants Committee reported that “chronic under-investment was to blame and that the major lack of investment in the health service made the delays inevitable”.¹⁴ Financial constraints were also highlighted as a contributing factor in the ‘Elective Care Plan, Transformation and Reform of Elective Services’ report published in February 2017. However, the plan suggests service modernisation and reform needs to take place otherwise the only option is to continue investing large amounts of money, which will not solve the problem.¹³ Whilst previous service improvement strategies have focused on increasing capacity the reform actions highlighted in the latest plan aim to address the increases and variances in demand to ensure resources are maximised and patients are seen by the right person, at the right time and in the right place. This means a range of alternative pathways should be put in place to treat patients out of hospital. However, currently the plan is “subject to the resources available to the Department”.¹³

1.3.3 Workforce planning

The Department of Health report also highlights that the delivery of care has been impacted by increasing challenges in recruiting and retaining the medical and nursing workforce. For example, over the past few years there has been a decline in the number of trainee doctors entering specialty training with 175 entering in 2013 and 109 in 2015.¹³ In November 2016 a shortage of specialist staff was reported with vacancies in 40 radiologist posts as well as a shortage of specialist orthopaedic surgeons.¹¹

The Northern Trust is being charged up to £100,000 a year for some of its agency nurses. This was due to a failure to recruit enough doctors and nurses to vacancies. The Trust said that while they are looking to recruit people to permanent posts, the failure to do so means that they have to hire agency staff who can cost three to four times the price of Trust-employed staff.¹⁵

There has been a growing number of medical vacancies at Consultant and middle grade.¹³ In a news report in November 2016 Dr Carson stated that the health service currently has to fill 118 Consultant posts due to a lack of trainees. She reported that “Northern Ireland has become a less attractive place for specialised Consultants to work in, and together we must change this if we are to attract and keep our highly motivated and skilled Consultants”.¹⁴ This not only impacts on waiting times, but on the overall cost of elective care, as the amount spent on medical locums has doubled from £22.5million in 2010/ 11 to £46.3million in 2015/16.¹³

1.3.4 Increasing gap between capacity and demand for elective care

Another cause of increased waiting times outlined in the Department of Health report indicated an increasing imbalance between demand and capacity. Demand for service has increased with a steady increase in referrals. Staff are being put under more pressure but capacity has been unable to keep up with the limited resources available especially due to an increased number of acutely ill patients presenting to acute and unscheduled services.¹³ The report also highlighted coordination of patient flow as important during periods of increased pressure on available beds arising from unscheduled admissions to hospitals which impact on the postponement of elective care procedures resulting in further delays.¹³

2.0 What we did

The PCC 2017/18 Business Plan includes the following objective:

The Patient and Client Council will seek to understand the experience of people waiting longer than Ministerial waiting time targets

The PCC will gather a number of case studies to understand the experience and impact on patients waiting longer than the Ministerial target for treatment and care, with a focus on the information available to people to enable them to make informed decisions.

The PCC will formally report the findings to health and social care bodies including the Department of Health, the Regional Health and Social Care Board and HSC Trusts.

The approach adopted for this project was two phase. Firstly, a large scale questionnaire followed by qualitative in-depth case studies.

2.1 Questionnaire

A scoping exercise of the topic area indicated a number of relevant questions which shaped the PCC questionnaire. The questionnaire was that piloted by PCC members. The final modified questionnaire was approved by the PCC Research Committee.

Questionnaires were completed via face to face interviews with the general public. Paper and online questionnaires were also completed by members of the PCC membership scheme.

2.2 In-depth interviews

Nine in-depth interviews were completed with participants on a one-to-one basis by PCC Personal and Public Involvement (PPI) officers. Interested individuals had expressed their willingness to take part in interviews when completing the questionnaire and these nine individuals were chosen to represent a number of specialty areas. The interviews were summarised into case studies and written consent was obtained for their use in this report.

3.0 What people told us

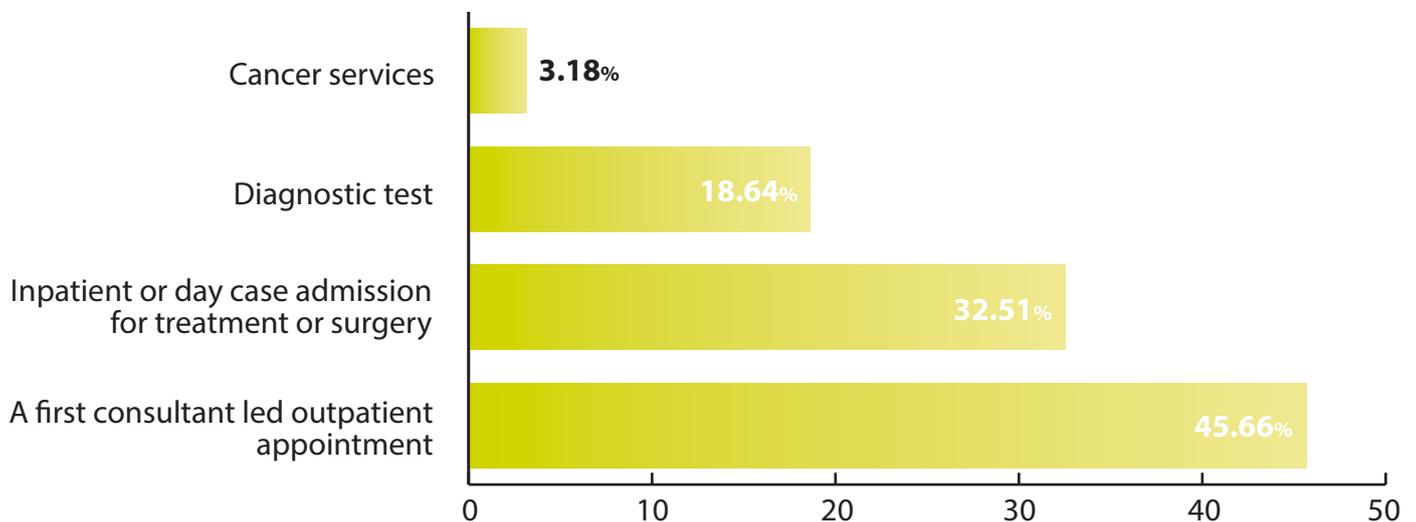
The results below are from the analysis of 692 completed questionnaires. Participant demographics are included in Appendix 1.

3.1 Participants experience of being on a waiting list

3.1.1 Type of hospital waiting list participants were on

Most people we spoke to were on a waiting list for a first Consultant led outpatient appointment (N=316) while over 30% of people were on a waiting list for inpatient or day case admission for treatment or surgery (N=225). The remaining participants were either waiting for a diagnostic test (N=129) or cancer services (N=22).

Figure 1: Type of hospital waiting list participants were on

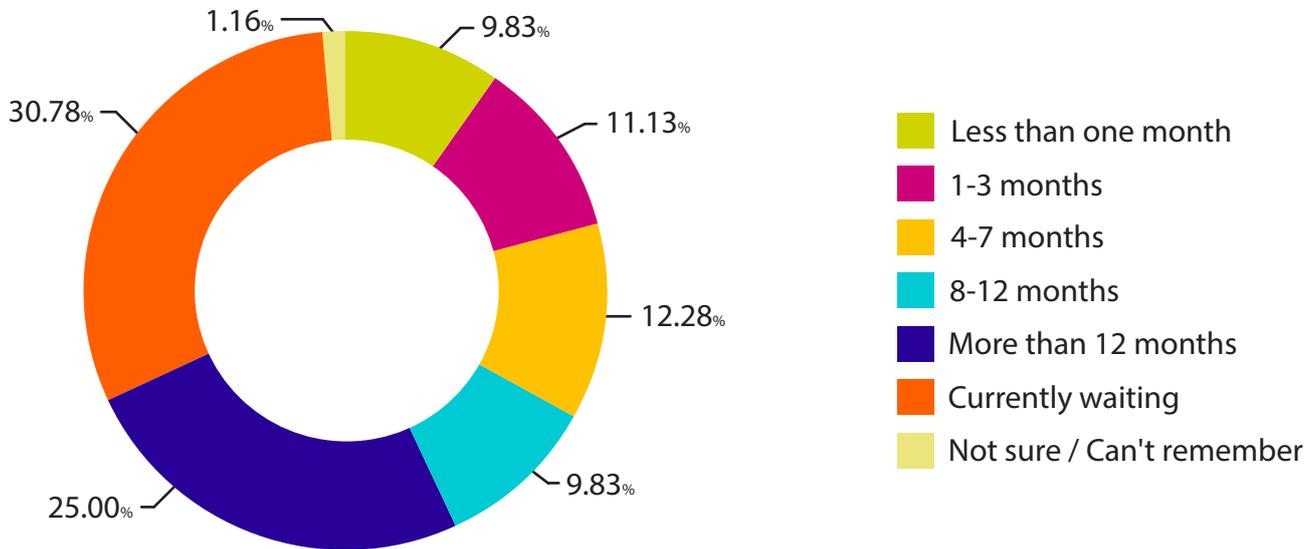


The top ten specialty areas that participants were waiting on were: Diagnostics (N=170; 24.57%), Trauma and Orthopaedics (N=129; 18.64%), General surgery (N=72; 10.40%), Ear nose and throat (ENT) (N=40; 5.78%), Gynaecology (N=37; 5.35%), Ophthalmology (N=31; 4.48%), Urology (N=27; 3.90%), Cancer (N=26; 3.76%), Pain management (N=22; 3.18%) and Neurology (N=18; 2.60%).

3.1.2 Length of time participants had been waiting

A quarter of people we spoke to were on waiting list for over 12 months (N=173) while approximately 40% (N=298) of people had been on a waiting list for less than a year before getting an appointment.

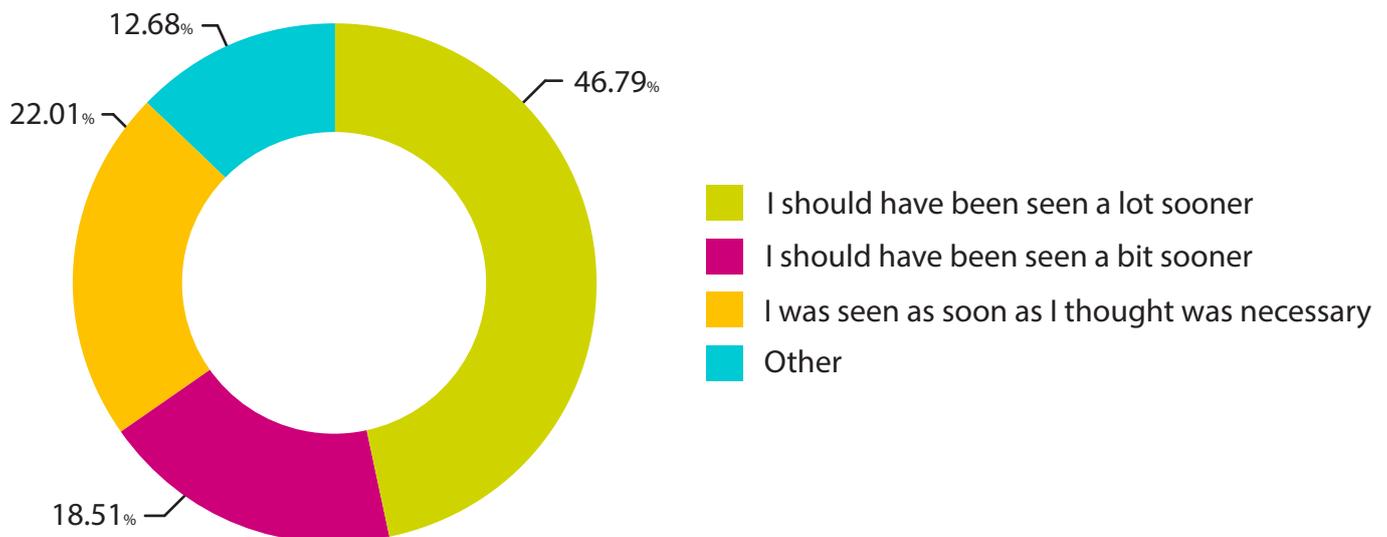
Figure 2: Length of time participants had been waiting



3.1.3 Participants opinion on the length of time they had been waiting

When participants were asked what they thought about the time they had been waiting over 65% thought they should have been seen sooner (I should have been seen a lot sooner N=321, I should have been seen sooner N=127). Approximately 20% (N=151) of participants felt they had been seen as soon as necessary.

Figure 3: Participants opinion on the time they had been waiting



When we break this information down by how long participants had been waiting, we can see that of those participants who had been waiting over 12 months, 89.5% felt they should have been seen sooner. While in contrast of those who had only been on a waiting list for less than one month, 86.8% felt they had been seen as soon as was necessary.

Comments from those who thought they should have been seen sooner included:

“After one year and 10 months I was given a date for admission only to be cancelled prior to admission due to no beds. Ten months later I am still waiting. I have been called again this week for another pre-operative assessment.”

“Two and a half years and still on the waiting list, even after seeing the Consultant and signing consent forms for the procedure.”

“A lot of information I had to find of my own back. I realised there were personality disorder services and the hospital were telling me there was no services and that they couldn’t help me. Three years later I’m referred and still waiting.”

“Absolutely disgraceful that I am waiting since April 2016 and can no longer be seen by a Paediatrician as I am too old. I have had a chronic condition since age three and have been referred to adult services now. It feels like I am forgotten about.”

“Told two month wait by GP. Phoned hospital told 14 month wait. Have waited one year at this point. Be honest with people. Support them to make informed choices.”

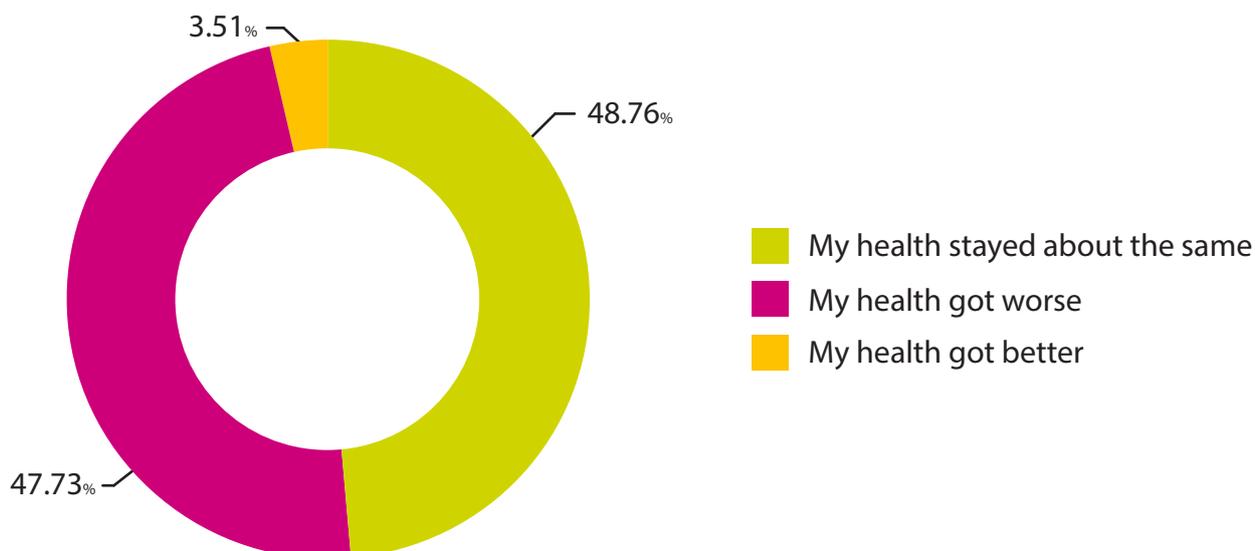


3.2 The impact of being on a waiting list

3.2.1 The physical and emotional health impact

Nearly half of the individuals who responded to the questionnaire said their health stayed about the same (N=333) while they were on the waiting list while the others said their health got worse (N=326). Only 24 participants said their health got better.

Figure 4: How was participants' health affected while they were on the waiting list



289 participants provided further detail as to how their health had been negatively impacted while being on a waiting list. The most common health impact that people identified was worsening pain with over a third of participants (N=111) describing how their pain had increased while being on a waiting list.

Examples of what participants told us include:

"The pain was so bad I could neither stand, sit nor lie without suffering and constantly taking strong painkillers. I had to pay to see a private consultant who greatly reduced my level of pain. My NHS consultant appointment was another 18 months later, a wait of nearly two years to be put on another waiting list for a chronic pain clinic. The stress factor alone has caused further complications on my health."

"I used to be able to manage the pain and go about my daily business, now I am very restricted, I can't walk without using some sort of aid. The pain is immense."

"I need my gallbladder removed. I have already had a scan to show stones blocking the neck. I am in constant pain. I live on anti-sickness tablets and painkillers and eat little."

“My situation has significantly deteriorated; knee joint has got worse with excruciating pain. I now can only access stairs with great difficulty. It is my left knee which needs replacement, therefore this has greatly affected my driving ability and I now depend a lot upon my family to drive any reasonable distance for me. At night to get sleep I have to sleep with my leg propped up with pillows and currently I sleep for approx. three hours at any given time.”

“I am aware that many people require surgery more urgently than I do, but I have been waiting for over a year and have been in so much pain that my ability to sleep and university test scores have been affected.”

“I found that I was more reliant on pain killers and this was affecting my stomach. I was experiencing bowel problems due to the medication.”

The negative impact on mental health was the second most common issue mentioned by participants (N=32) when describing the health impacts of being on a waiting list. Decreased mental health was often attributed to living in pain or dealing with the uncertainty of waiting on appointments.

Comments people made include:

“My health has deteriorated both physically and mentally. It is very depressing to be practically immobile and to be on pain killers.”

“The worry of what the outcome might have been had a knock on effect on my mental health, which resulted in me requiring further services.”

“Stress due to the uncertainty added to my symptoms.”

“The pain I am suffering has increased my anxiety levels and I am very depressed. The pain is draining me and I have lost my appetite completely.”

“You learn to adjust and put up with your situation. You begin to feel apathetic about it and give up and get depressed and lose heart.”

“My fertility was declining the whole time I was waiting; something I could ill afford. Even once seen I had to wait a further three months for test results and a review appointment. All very bad for my mental health. I felt a huge disruption to my day to day life as I was constantly worried about my condition.”

Other participants described how functions such as sight, hearing, continence and mobility deteriorated while being on a waiting list. In addition, people described the impact on various aspects of their health such as fertility, sleep, weight control and falls, while other participants spoke about a general decline in their condition.

3.2.2 The social and financial impact

Participants were also asked whether being on a waiting list impacted other aspects of their lives. Responses fell into two main categories; the impact on participants' social lives and their relationships with friends and family, and secondly the impact on people's working lives or education with people explaining how they had to reduce their hours or give up work completely resulting in a financial impact on participants and their families.

Social impact

"I am socially isolated. When I have been sick in the street people look at me in disgust."

"I am unable to make any arrangements or join in for family occasions, I feel bad letting people down which I find very disappointing and it leads to a lot of anxiety."

"I was not able to participate in many social activities. Those that I could attend were significantly impacted, for example, at a friend's wedding I had to dose myself regularly with painkillers and anti-inflammatory drugs just to get through the day. I couldn't play with my grandchildren and had to have another adult assist when out with them as I wasn't able to keep pace with them."

"Social life - what's that? I can't play football with my friends anymore, I feel like an old man before my time. I miss out on doing nice things with my children as I'm almost all the time on a stick."

Financial impact

"I had more days off work with this than I have ever had in my whole life. I don't get sick pay at work only the statutory sick pay from the government and this has a huge impact on everything we do as a family. For example this year we won't be going on a summer holiday as I normally saved throughout the year to pay for this but couldn't this year. My son didn't get to go on a school trip because we really couldn't afford it."

"Big financial repercussions in being unable to return to work and having to retire early."

"Financially - I am a midwife and had to take sick leave, this meant I lost my special duty payments. Felt pressure to go back to work; have to support my children who are at university. Also had to pay for private physio."

"Had to drop out of college, I was too unwell to live alone."

"Had to go on the sick in May which I lost in July - I work in agriculture and heavy lifting . . . so I was left at high risk."

"I am struggling with my course and to find employment due to my condition."

"Lethargy means I am less likely to get up and do things. I have dropped a day in work due to fatigue which leads to less money. I should add I work for the health Trust and feel demoralised working for something I no longer have faith in as they have failed my wife and me on numerous occasions over the past two years."

"I had to retire six months ago, this has affected me both financially and mentally. I have worked my whole life and I've never had to depend on anybody. Now my children have to do everything for me. I find that extremely hard."

Being on a waiting list also resulted in people feeling that their lives were 'on hold' as they could not make plans, such as going on holidays, for fear they would clash with the appointments they were waiting on.

"I feel my life is on hold. I'm crippled every day. Feel it gets me down a lot and think when is this going to end."

"My life is on hold, because I don't know what is happening... when will I be seen, how long will I wait. Not knowing is terrible."

"Cannot plan holidays because I am afraid I will miss surgery and have to wait even longer."

"A lot harder to do anything. Terrified to make plans in case I get a cancellation."

"Emotionally very hard to be in limbo. Difficult to plan ahead."

3.3 Additional issues related to waiting lists

Within the questionnaire, participants were given the opportunity to highlight any other issues or comments they may have had.

3.3.1 Lack of fairness

One issue that was raised a number of times was the lack of fairness in waiting list processes. When discussing this issue people mainly referred to the inequality between NHS and private services but there was also a perception that access to services differed depending on where you lived in Northern Ireland. One participant also highlighted how they felt 'vulnerable' and unable to complain about the service they received for fear they would jeopardise future treatment.

"Angry at inequality in service. Wish I could jump the queue by going private but hate two-tier system."

"I don't blame the people who operate the waiting list but the system is flawed. I was able to get an appointment with a private Consultant the next day and he was the NHS Consultant I should have seen."

"I felt forgotten about. Through using savings I obtained a private consultation immediately which made me realise how unfair the system is."

"Didn't feel there was enough rationale or fairness behind the process."

"Feel like lists are shorter if you lived in Belfast."

"Felt I couldn't ask questions, felt if I did then I could be badly treated and my surgery could be postponed further. Felt I had to put up and shut up. Felt vulnerable in the hands of others and felt that if I asked questions my treatment would be jeopardised or not as good. Didn't know who to turn to for advice. Felt I was never given all the information I needed."

3.3.2 Wasted resources

Another issue that was of concern to participants was the resources that were wasted while patients were on waiting lists, for example, the cost of medication to manage symptoms, inpatient hospital stays which may have been avoided and the additional burden on GP services.

"I was placed on the waiting list in March 2016. Since then I have been admitted three times with severe gall bladder infections including a 13 day inpatient stay."

"Because of the length of time I was on the waiting list I visited and used far more services. In this time I visited the GP more than I have in my whole life so far."

"I have had three separate procedures in the last three years. In every case I have had to waste my GP's time trying to find out when or even if I am still on the waiting list."

"Surely it would be more beneficial for the government to sort out the waiting lists... I know I'm a huge drain on the system but I can't help it. My mental health is affected by this pain and I'm taking so much medication I wouldn't like to think how much that cost, never mind the amount of times I have to attend my GP. I'd say if you counted up my medical bill for the two plus years I'm waiting I'd think you would have paid for private operation for me."

3.3.3 Lack of 'joined up' approach

The lack of a 'joined up' approach in healthcare was also flagged as an issue. People referred to the lack of co-ordination between different departments and hospitals when waiting for treatment and care and some participants also highlighted how they had experienced a breakdown in communication between services when they had accessed healthcare privately. There was also a perception by some participants that there was a lack of consideration given to how problems accessing health services have an impact on social care services i.e. living with poor health results in more people availing of benefits.

"System is not joined up, I'm waiting for three different procedures and they don't talk to each other. I felt scared into keeping appointments that were made by the hospital as they told me I wouldn't get another one for three months. They don't give you any options."

"When I did get my appointment, they were with two different Consultants which to me was a waste of money. However, when I went to the first Consultant to have a colonoscopy, I asked if he would do the OGD on the same day, which he did. I feel I was the one who acted wisely. Then I was able to cancel the other OGD appointment saving money to the health service."

"The departments don't communicate with each other at all, they are duplicating work."

"My records from going privately are not on the NHS records. Getting linked back to the NHS is problem."

"No joined up thinking - health and social care don't work together. Health could have got me back to health so that I could have got back to work and pay my taxes. Wanted me to go on income support when I wanted to work."

3.3.4 Absence of patient centred approach

A number of participants alluded to fact that they felt a patient centred approach is lacking in the current model of healthcare provision.

"Feel in general that the waiting lists are far too long... and the patient centred care is non-existent at the moment."

"Doctors should treat patient as a whole and not just the problem in front of them."

"I am young, but have a condition that is getting worse the longer it takes to be seen. I can't imagine what it must be like to be elderly and left in this predicament. Health service are always banging on about how we are all living longer, but are not doing anything to combat the difficulties people are having with services to keep them well for as long as possible."

3.3.5 Support for healthcare staff

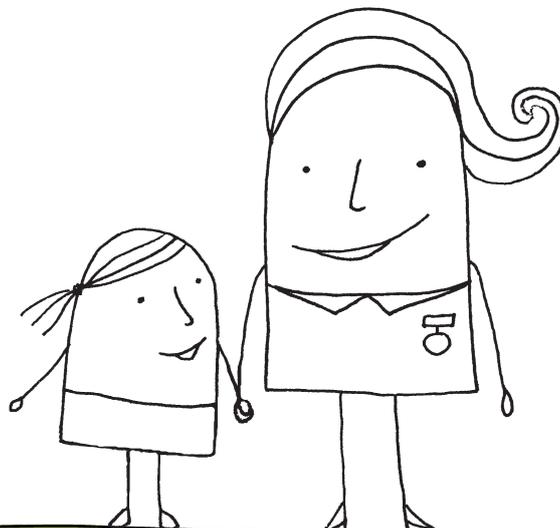
It is important to highlight that numerous participants emphasised how they did not blame healthcare staff, either clinical or administrative, for the waiting list issue as they believed it was out of their control. Many participants stated that they felt the waiting list issue was a result of system wide issues and was particularly influenced by the lack of Government leadership.

"Everybody I deal with are all very professional and very good, but it's the money that's the problem."

"I feel sorry for staff in the central booking unit as they are the ones who have to deal with people's dissatisfaction of waiting list lengths even though it is totally out of their control."

"I blame our "Government" for the delays in what is otherwise a brilliant Health Service. The blame lies totally at their door."

"The system is clearly the problem, I have a lovely GP who does as much for me as she can... we have two new hospitals in this area and still I'm waiting too long, why? The government are in no hurry to get back to work, to roll out what seemed to be a promising solution to hospital waiting lists that was being rolled out by the old health minister before the collapse of Stormont."





Case studies

Case Study 1 - 18 year old male, student

My son has Cyclical Vomiting Syndrome (CVS). When he was younger he was seen regularly every three months but when he turned 16 we were told that it wasn't appropriate for him to be treated in the same hospital department anymore and he was referred to adult services in two other hospitals. Recently I phoned the hospitals to update them to a change of address only to be told that the waiting list is currently three years, so he is a long way off getting an appointment.

My son's transition between services has been handled quite brutally really. We last saw the Consultant in children's in April 2016 and we didn't know she had discharged him until I phoned up for another appointment when I was basically told that he was too old and had been discharged and referred on. We had been told previously that he wouldn't be discharged from Paediatric services until the doctor found someone else who could see him, as they knew there was a long waiting list for adult services.

Our GP got in contact with the Consultant on our behalf to say that the way my son's transition between services was handled was inadequate. The Consultant informed our GP that she had referred him on to adult services and had presumed he would be seen. However, the hospital she originally referred him to said they couldn't treat my son and it was they who arranged the further referrals to two other hospitals.

My son's symptoms are migraines and what is known as an abdominal migraine as well as persistent vomiting, six times hourly. Currently he has been referred to one hospital for the migraines and another for his stomach but he really needs to be seen by someone who can deal with all symptoms as it is one condition.

I am also on a Neurology waiting list myself for a review appointment, the Neurologist I usually see is off on long term sick and there is no replacement. I am waiting since April 2017 for my regular three monthly appointments. It is very distressing at times when I have a flare up and no one can advise me on treatment. So waiting list issues have hit our family twice.

Neither my son's condition nor my own can be treated by the GP that is why we need the specialist appointments with Consultants. If I thought there was a cure for either of us, I would be going down the private route. I have previously gone private for another condition I had. I worked in the NHS for thirty three years and I am very much against going private, but for my own health, I had to do it. I am just very disappointed by the whole situation.

Being on the waiting list for so long you feel like nobody really cares, it makes you feel very anxious. It is a rare condition that my son has and it has left us feeling that there is nobody he can turn to. He has been totally left on his own as a teenager to manage his condition. The last time he had an episode he went to the GP only to be told that they couldn't do anything because he is under the care of a specialist, but he is not, because he has not been seen! We

actually had to make the decision as parents to try to juggle medications to see if that would help him.

There is a charity in England for CVS which I am a member of and I was in touch with them last week, and they just seem to have a far better health service. They would have district nurses calling to the house and they also have like a fast track service in their hospitals for the condition as well.

Recently we were asked to complete the forms to transfer from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). On the forms I had to put down the Paediatrician's details because my son hasn't seen another Consultant but because he has been discharged from that service I doubt very much if they will provide information. Luckily our GP was very supportive but this could have a financial impact on our family.

I think it would be really good for hospitals to keep you updated by email or letter. In the past I remember receiving letters to tell you that your referral had been received and that they would be in contact but I haven't received anything like that in recent years. At least if they sent you something you would know you were on a list somewhere. I feel totally forgotten about. Overall the experience of my son being on the waiting list has been disappointing, very lonely, and desperate at times. There was just no support.

Case Study 2 – 59 year old male, employed

My issue was with my hip. Part of my problem is that I was delayed in getting a diagnosis. I was attending Physiotherapy for back pain and it was the Physio who felt that the pain wasn't coming from my back so they got me referred for an x-ray. When I went back to the GP for the results I was told my hip was in a bad state as the two bones were rubbing against each other. I was truly shocked.

From talking to the GP and Physio at that point I learned that I could be looking at a wait of two years plus for a hip replacement. Initially I was referred to orthopaedic ICATS rather than straight to a Consultant. That team assess you and they may decide on various treatments, if it's a really serious situation then they will refer you on to the Consultant. I was told the waiting list for ICATS was 12 weeks but because of the pain I was in and the amount of painkillers I was shovelling into me, I was phoning them once a month to ask what the situation was. I kept getting told that they were getting appointment letters sent out and then a further four weeks on I was still getting told the same thing. I eventually got very annoyed on the phone and said "look you have told me the same thing for a long time which is not right, you are supposed to see me within 12 weeks. I understand that 12 weeks is a

target but realistically this isn't going to happen." At that point I was assured I would get an appointment to see their Doctor and that they would be sending a letter out to me.

When my post arrived the next week, I got two letters, one telling me the appointment date and the other telling me it was cancelled! I got on the phone and asked what was going on, I was told that the Doctor was sick and they couldn't tell me when I was going to be seen. I told them I wasn't happy and wanted to raise a complaint at which point I was told they didn't have anywhere to complain. I nearly fell of my perch because I work in the Trust and when I started out I was actually working in complaints, they have a well-documented complaints procedure.

Eventually a senior manager phoned me to discuss the problem. I asked if she had seen my x-ray, which she had, and I asked why I was being referred to the Doctor who was going to tell me I needed to see a Consultant. Why not send me straight to the Consultant? I was fairly fortunate that she actually conceded on that and agreed that I had been messed about so I received a referral straight to the Consultant. That was mid-July and I saw the Consultant around the beginning of September. When that letter came in, it was like the lottery or something, it was great. I think I struck it lucky because a new Orthopaedic Consultant had just been recruited and they had no waiting list. When I saw the Consultant he confirmed that I needed surgery and told me it would be about 3-6 months. To be quite honest I was delighted because I know people waiting two years. It was almost six months to the day when I went in for surgery.

It wasn't a straightforward process but I know the system as I work in the Trust. I knew who to phone and I was persistent, eventually the message got through. Quite honestly, I think that if I hadn't had that information and I hadn't been on the phone, I wouldn't have had my hip done by now.

In regards to the length of time I was waiting, I know I was lucky to have my operation done 12 months from I was first diagnosed. But when you are living on pain killers, you are walking on a stick, and you can't walk more than two yards, it's not good enough. The pain I was in was debilitating. It had a big impact on my family life, doing activities with the grandkids or going on a break with my wife. We love having a weekend in Donegal but we had to really cut back because the long drive left me in such pain and when we got there, there wasn't much I could do anyway. I was probably more prone to sitting in the house watching TV rather than being out and about.

I would have liked more information while being on the waiting list. If you were told you were moving up the list that would be a help, at least you would have the satisfaction that things were progressing. I would be happy with any contact whether it is an email, text or whatever, just to tell you 'you are on our list, we are still managing your situation', at least you know that you haven't been forgotten. It's the reassurance that they know you are out there and they are working towards getting you in for your surgery.

I think the first word I would use to describe the waiting process would be worrying. As I have said before because I work in the Trust I had an understanding of how things operate, I found out who to contact. I think that if you weren't in that situation, with that knowledge, it would be a lot more stressful. I talked about my worries with my wife. I also raised them with my manager because I was concerned about my sickness leave in work. I was worried because had I not got the surgery in good time the odds were that I wasn't going to be able to keep on working. I am fortunate that I am able to work from home. There was quite a number of days where I came downstairs plonked myself in front of the computer with the phone beside me and worked from there.

The not knowing is probably the worst part. If they had of told me at the outset it will be a two year wait for your surgery I would have been pretty distraught but if they could have guaranteed it wouldn't be longer than that I could have accepted it. But saying it could be three months, it could be six months, it could be nine months was awful.

Case Study 3 – 40 year old female, unable to work

I went to my GP in May 2014 as I had a sore shoulder. The GP gave me painkillers but they upset my stomach so I was referred to Physiotherapy. I had ten sessions of Physio but my pain was absolutely no better, if not worse! I was then referred for an x-ray, but it didn't show up a big pile. After the x-ray I was given an injection into my shoulder but it didn't help the pain either. The GP decided that I should have an ultrasound, which I had in April 2015, and it showed up that there were two bones rubbing together. As a result I was going to need surgery.

I was put on a waiting list but my GP told me the waiting lists for Orthopaedics were very long, eight or nine months. My GP informed me that I could go to see a Consultant privately which I decided to do but I was told it would cost between £100 and £125 for the appointment. I saw the Consultant in May 2015 and was put on a waiting list for surgery and I am still on it now. It has been two years and six months, but I have been given a date for December 2017. I just hope they don't cancel it and I hope I don't have to cancel it either.

When I was first put on the waiting list I used to ring them up every month. Initially I was told it would be twelve months but then that became fifteen months and then it was eighteen months. I just got fed up ringing them then. I said to my doctor when I was put on the waiting list to make sure they knew I was available for cancellations, and I even said it during some of the telephone calls that I made to the receptionists/secretaries but I had to run after them.

One day I got a phone call from the hospital to ask if I could attend a private hospital to discuss my surgery. At the appointment, about two weeks later, I discussed my shoulder pain with the Consultant who said he could see I needed surgery and agreed that physio would be of no use. I asked if I could be marked as an urgent case which the Consultant did, but he explained that it wouldn't make any difference and that there are far more urgent cases on the waiting list.

At the appointment I asked the Consultant about paying privately for my surgery but he informed me that it would be very costly, anywhere between six and nine thousand. At the time, I really hadn't got the money to do it. I do know of people who have had their surgery in the Republic of Ireland but I didn't look into it because I have waited this long.

When I was initially put on the waiting list I was on maternity leave. As I was told I would be waiting for eight or nine months I had planned to use unpaid maternity leave and other annual leave to cover some of the time off while I was waiting to have the surgery and get back to work. Due to the fact that I wasn't seen within the nine months, when it was time to go back to work they were hounding me. I took unpaid maternity leave, I took parental leave, I took holidays, I took everything I could take to try and prolong it. In the end I had to hand in my notice because it was either that or they were going to sack me. I felt I had no other option than to hand in my notice as I didn't want to have it on my record that I had been let go because I wanted to be able to get a reference if I went for another job. It was so disappointing because I had been in a job share post that allowed me to work part time, which was ideal in my situation. I handed in my notice in January 2016. Having to give up work has had an enormous financial impact on my family even though my partner is on a good wage. When I was working we were able to do anything we wanted, I would love to be able to go back to work. Socially I miss my work colleagues.

I don't know whether there is any more damage done now in my arm than there was when I first went to them but I am now noticing that I am developing pain in my other arm. It's hard to do everyday things, to move it at all is sore, even to clean a window, put your clothes or do your hair. I am taking extremely strong painkillers every day, they are giving me stomach problems and now I have to take additional medication for my stomach.

The information I got kept changing. It would be good to have more accurate information. I was waiting all the time to see if I would get called. Other than getting the call to see the Consultant no one ever contacted me with any information or updated me. It would be nice if somebody rang you up and gave you an indication of how long, but every time I rang them up, I was told I would be waiting longer and longer. Even twelve months it's long enough, but two and a half years is definitely too long.

Case Study 4 – 72 year old male, retired

I have just recently had an operation to have my shoulder replaced. I waited for two years and 10 months to get this done. I am also on a waiting list for carpal tunnel syndrome. I recently phoned up to enquire where I was on that waiting list and was told that they are currently calling people who have been on the list since June 2016. I have been on the list since March 2017 so I expect I will be waiting another 10 months at least.

Initially when I went to see about my shoulder everything was straightforward. I went down to my local health centre and saw a Doctor. I was referred for an x-ray which I had about one month later then referred on for a scan which I had about six months later. That's when it all came to a standstill. When I had my scan for my shoulder I was told it would be quite a wait to see a Consultant. It was suggested to me that if I was willing to pay, I could move up the list quicker to see a Consultant and I could then be put on another waiting list for the actual operation. I didn't realise just what the Doctor meant by the waiting time until I phoned the hospital and they told me the waiting list was 51 weeks and then, three months later when I phoned again I was told the waiting list was up to 66 weeks. At that stage I thought I was never going to get the surgery done.

In the end I actually went private and paid £3000 to have the shoulder operation. When I was brought round after the operation the surgeon said there was nothing he could do because of the long wait the damage had been done which couldn't be repaired. That was £3000 out of my pension pot that could never be replaced. I had plans for that money, my pension is the only source of income I have. The surgeon suggested that he would do what was called a reverse shoulder replacement, where he took out this joint and put in a plastic joint and he said it would give me a bit more support. He said it would be about £10,000-£11,000 to have the surgery privately, which I could not afford but he said he would do it on the NHS and there would be a six month waiting list.

When it came to the week that I was to have the surgery I was phoned on the Tuesday to confirm my appointment for Thursday at 11 o'clock in the morning. Then later that afternoon about 4pm I was phoned back to say there were no beds and not to come in. That ended up being another six month delay.

When I was put on a waiting list I was aware that a lot of people are currently waiting longer than the targets. I go to a diabetes group and we all have something wrong with us apart from diabetes, so talking to other people you do hear some horrendous stories and I'm not the worst. When you are on a waiting list every day when the post drops through the letterbox you're hoping for the brown envelope, but it doesn't come. You find that you cannot do things as the pain is getting worse. I had done voluntary work but I had to give that up, now I'm in my 70s I don't know whether anyone will want me for voluntary work. I started to get a bit depressed because being on your own practically everything you do in the house you need two good hands for. Even simple things like lifting something in and out of the

microwave you need two hands for. When I was hanging washing out on the line I had to put steps up because I couldn't lift the clothes up.

At times I thought, is this how I'm going to end my life sitting in the back room looking out watching the birds in the garden. Even when the window cleaner came I'm sure he hated the fact that I was in because I might not have been speaking to anyone for two or three days so of course the company was great. If I hadn't had good neighbours I would really have been in trouble.

I get embarrassed going to the doctor. I seem to never be away from the doctor. I don't like to ring up the hospital because I know they're busy. You have to ask yourself "do I really want to know this?", or shall I just sit and wait until the letter comes. I think if they sent you an email at least it may have more information than someone just telling you that you will be waiting 66 weeks. I don't know why they don't want to give us this information. I think it's wrong that as a patient I have to keep chasing up the hospital. Why can't they email us every three months to give us an update? I don't want these people to come to me and say look you will be seen in 52 weeks, I want them to come back after 3-6 months and say this is what we have done, we have reduced the list and you are so far up the list. I think that the people who set these targets don't really know what they are talking about, they must be able to come up with something closer to the actual time you will be waiting.

My experience of the waiting lists was a nightmare. I would tell anyone who could afford private health insurance to take it but we can't do without the NHS because not everybody would be able to afford a private hospital. I'm still paying national insurance and then when I need surgery somebody is telling me 'tough, there's nothing we can do'. I believe that we are never going to solve the problems in the health service until we get rid of waiting lists.

Case Study 5 – 79 year old female, retired

I have Carpal Tunnel Syndrome in both hands although my right hand is worse than my left. Carpal Tunnel Syndrome gives you a burning feeling in your hands and makes them numb. It's a strange pain as if your hand was on fire. It makes it very hard to do the simple things that you do every day. It is terrible and it's getting worse.

I was initially seen in hospital to have splints made and then I was seen by a Consultant but that was three years ago. At that time the Consultant explained that I needed surgery and told me he was going to "push this on" for me. Because of what the Consultant said I believed

I would be seen within a couple of months although when I went on the waiting list I was told there was a two year wait. My GP was very helpful and sent a follow-up letter but I don't know how much longer I have to wait as I haven't rang the hospital recently, I just got fed up of asking. The last time I rang I was told by the receptionist that I hadn't made it to the surgery list yet and to keep taking my tablets.

There has been no other support offered to me to manage my pain other than pain killers and splints. I take my tablets. I only take one in the morning and one at night. I don't want to take too many because I'm on other medication for other health conditions. If I didn't take the painkillers the pain would wake me from my sleep. I wear splints, but they don't give me much relief and I have to take them off during the night because they get too hot and too painful. Sometimes I have to use a sling to keep my hand elevated.

The pain I have because of Carpal Tunnel Syndrome has meant that I can't do activities that I used to enjoy. I used to like water aerobics but I have had to stop going as the pain in my hands means I can't hold on to the side of the swimming pool. I am worried because the pain is terrible. It also makes your self-esteem very low, for instance if I am paying for something at a checkout I have to ask the cashier to lift the change out of my purse. I also have to ask my friends and family to do simple things that I am unable to do. They forget at times that I can't do things as easily anymore.

I am concerned that as I have been waiting for so very long that my condition may deteriorate so far that it will be inoperable and yet I was told by the Consultant that I needed this done soon. I know of other people who have had surgery much more quickly and it makes me feel that when you are in the senior citizen age group they don't care about you. I had considered recently ringing the hospital but I am so afraid of being told I am still not on the list for surgery.

I would like them to give me information on what is happening. I wasn't told if I could be put on a cancellation list, if I got an appointment or a cancellation I'd go in the morning. When you are in limbo I think it would make a difference to receive better correspondence, to give you information on what is happening. I think it's very degrading, to let you wait so long. Those making the decisions in healthcare have no idea what people are going through. They don't know what it's like to go through the pain.

Case Study 6 – 58 year old female, employed

I am currently waiting for an operation on my knee as I had a bad fall nearly two years ago. At the time of the fall I had just been given a compression bandage but I had to go to the GP as the pain was getting worse and worse. The GP recommended Physiotherapy and an MRI but explained that both waiting lists were long so he advised me to go private, which I did.

The MRI showed that my knee was badly damaged; I had torn the meniscus, so I was referred to the Consultant and seen within a matter of weeks which I thought was great. On the day of the appointment I had forgotten to bring the CD with my MRI images but the Consultant told me to drop it in to the hospital and advised me that the next appointment I would be called for would be my pre-operative assessment. That was it then and I never heard another thing. That was about a year ago. My GP phoned the secretary and was told that it is a routine operation and the usual waiting time is 20 months after you have a consultation. I am currently waiting about 52 weeks which is over the ministerial waiting time. The secretary estimated that my surgery will be in December 2018 which would mean I will have had to wait about 24 months.

I would like more information about where I am on the list. If I knew where I was on the list then I could keep a record and know if I'm going up or down. I wouldn't care how they provided it, I would just like the information. Not knowing when I am going to be having surgery has had a major impact on my life as I am afraid to book anything or go anywhere because I want to be available if I was sent for. It has also had a wider impact on my family, I used to mind my grandchildren, now my daughter has had to go part-time and the grandchildren go to crèche, so that has had a financial impact on her.

It's terrible that I have to go through another year of this pain. Even getting up in the morning, the minute I put my foot to the floor it causes me pain. My leg buckles under me. I feel like I am a nuisance to everybody else. I went on a coach trip recently and even getting up and down the steps of the bus was hard. You just feel totally useless. The pain is horrendous, it just stops you from doing anything you want to do. I had a holiday booked with a friend but I had to cancel because I knew I wouldn't be fit. It just gets you down. I know there are people worse than me, but nobody should have to suffer this long. This situation has had me in tears, they don't consider the person how they are coping. I would say being on the waiting list leaves you feeling depressed.

I feel that the waiting times are a disgrace, patients are suffering for the mistakes of the service. A few years ago a family member had two hip replacements done within a year. I don't understand how things have become so bad. I feel like I have paid taxes all my life and now I get nothing. People tell me to apply for Disability Living Allowance (DLA) but I don't want to be on benefits I just want my leg fixed. I can't afford to go privately for surgery and even though my family have said they will club together to pay for it I don't want them to be out of pocket. Why should they be put out for something that I should be entitled to?

Case Study 7 – 69 year old female, retired

I have been waiting on a total hip replacement since February 2016. Initially the GP thought it was a trapped nerve – sciatica and was concerned about how I was walking. I was referred to a Physiotherapist, which I was able to get an appointment for very quickly, that was in 2015. The Physiotherapist advised that I have an x-ray which showed advanced arthritis in my right hip. I continued to see the Physiotherapist for about three months but it really wasn't making any difference.

I was then referred to a Consultant who confirmed that I needed to have a hip replacement. At that stage I thought I should put off the surgery as I could cope with the pain. Approximately six months went on and I was referred by my GP back to the Consultant as my pain was getting much worse. I went back to see the Consultant in February 2016 and was put on the waiting list for surgery. I felt it was partially my own fault that the hip had got in such a bad state because I had tried to avoid surgery.

At my appointment with the Consultant I was told I needed to have surgery as soon as possible as I was going to need surgery on the other hip too. The Consultant told me that he would do his best to get me on to the list as soon as possible. He did not give me a time but I had assumed I would have only been on a waiting list for a short period of time. It was probably presumptuous of me to assume that I would be seen in 6-12 months but once I was past the 12 months it became very frustrating because I was getting much worse. I had retired from work because I couldn't sit, I couldn't do the job that I am trained to do.

I had my pre operation assessment in February 2016 and was given a pre op bag home from the hospital to say that the operation would be within 13 weeks and that they would be in touch with me. The 13 weeks came and went and then in July 2017 I was called back for a second assessment and was seen by a specialist Nurse. I was given the same procedure again and another pre op bag.

I have phoned the Consultant's secretary on a regular basis from February this year but she refers me on to the appointments department. I was told I was fourth on the list in July this year, I phoned again in August and was told the same thing. Following this the Consultant was off for a period of time so as of September I am still fourth on the list. I haven't phoned recently as I have just given up on it. My GP has been very helpful and has tried to chase it up but without success. It is difficult to know if there is any more I could be doing.

I had no information on who to contact about any updates. I did that of my own accord. I have given them my mobile and my house phone and have assured them that any moment of time if there was a cancellation, I would be there in five minutes. It is not getting any easier, I am sure there are others who are worse than me and of course they are entitled to get their operation first but this past year my pain has increased drastically and I now have severe pain in my hip and into my back. I attend my GP who has upped my pain killers but I find them

very hard to take as they cause side effects such as vomiting. It's horrible. I only try to keep the medication to a minimum and if possible use a rub.

Being on a waiting list makes you so grumpy. You can't go anywhere, you can't sit in the car and you can't walk. My husband and I would have gone on lovely walks and now I can't walk any distance. I loved the garden but now I find I can't do that either. I am not a very sociable person but I do go to a craft class but I am finding it hard to sit for long periods and the class is two hours. My husband and I haven't had a proper long holiday in two years. You can't plan ahead because if you got a call for surgery and couldn't come then you have missed that chance. I am putting my husband's life and my life on hold, just in case someone phones.

I don't feel I need more information, I just need an appointment. My condition has deteriorated dreadfully. If someone phoned me and said "you are going to be another six months", it's not going to make me happy is it? I don't think contacting the hospital has made one bit of difference. I don't think they recognise that I have been calling for 6 or 7 months but I know there is no point getting cross with the appointments department those people are just doing their job.

I would just love to go private but I just don't have that amount of money to spend. Even if I did, I don't think I would want to spend it on myself when I could use it for the rest of the family. Also, I don't think I would want to spend that sort of money when I could get it done on the NHS as I am entitled to.

Case Study 8 – 79 year old female, self-employed

I am on a waiting list for a hip replacement. I've had problems with my hip for a couple of years but it was only diagnosed within the last nine months. I never thought I would have needed a hip replacement although I was running to a Physiotherapist for treatment for pain in my groin and hip. I ended up spending money that I didn't need to spend if I had known sooner. Around that time I was attending a surgeon for my broken ankle and I told him that I was having a lot of trouble with my hip and back. He sent me for an x-ray but somehow or other it seemed to take so long to be diagnosed. I should have had the x-ray in April but didn't have it until August, everything was running behind. When the doctor seen the results he told me I needed a hip replacement.

When I went on that waiting list the doctor told me that it would be at least two years until I had surgery. However, the last time that I saw him he said that he cannot guarantee that I won't be on the list for three years. He said that his own mother was in the same position

and he had to send her privately to get surgery. I have no option other than to go and get it done privately and I resent it very much because I have worked all my life. I have employed a lot of people, we paid our taxes and I think it is very hard for older people to find that kind of money. It is going to cost £10,000, for my age group it's hard to find that kind of money. It is going to have an effect on us because I am not able to work at the level I was working to run our guest house.

Only that I am able to go privately I don't know what would become of me. I feel for the people who can't afford to go privately. I feel guilty because there are so many people out there waiting for hip replacements. I think people like me are ending up in hospital ill because they haven't had a hip or knee or whatever they are waiting to have done. It has a terrible knock on effect. If they would look after the older generation a bit better there would be a lot less of us in hospital and needing care. The whole thing is back to front. I know that if I carry on the way I'm going, taking the level of pain killers that I am taking, I'm going to end up in hospital for more tests because the pain killers have a negative effect on me. They are not designed to be long term.

The target waiting times that are set are reasonable and most people would be happy to wait that long, or maybe even a little bit over, but when waiting lists run into years that is not reasonable. I am waiting almost a year and if I hadn't been able to go private I would have been heading in to 2018 knowing that I have to face a whole year without any treatment and maybe into 2019 as well. For people having to face that – it is horrific.

Being on a waiting list impacts terribly on your wellbeing. I know if I don't try and do something in six months' time I could be in a wheel chair. I am struggling as it is but I make myself go on. I just have to get on with it as best I can and suffer the pain, but the pain drags you down. People end up being marooned in four walls. I just think it is so severe on older people. It is not something that is life threatening but it threatens your whole wellbeing which is nearly as bad especially when you don't know when you are going to get your issue fixed.

I run a guest house with my husband. I am probably very lucky because I am a strong sturdy person for my age and there are not many people do what I do. I have been teaching a cookery class for fifteen years and this is the first year that I had to let it go. I just wasn't fit to do the shopping or the standing to cook. I find that I just can't do the things I need to do, there are a lot of things in the garden I need to do and I just can't get them done. I am running behind because I am struggling and I am having to sit down I am not in the habit of that, I am used to be able to get on. I make sure I am tired so I am able to sleep and as long as I do that I am not too bad. That is part of why I need to keep working so that I tire myself, if I was sitting here unable to do anything I wouldn't be tired and at nights when you are lying awake your pain seems far worse.

I am fortunate, I have a husband and four daughters to look after me and I have great support around me, but I know there must be so many people who don't have that support. There are the people that we really have to be fighting for. I think something needs to be done so less older people end up in hospitals and care homes. If they don't look after people like me, who have great energy levels, who still can work there are going to be a lot of older people in hospital, the service is going to get worse because more and more people will be heading in to hospital.

I was told that if I cancelled or failed to attend I would get put back right to the start of the list. I think you should be given a little bit of flexibility with appointments, especially if you are still working as we are. It would be nice if they informed you earlier to ensure that you could arrange to keep the appointment date clear. But if anything goes wrong, it doesn't matter what it is, you are right back to the bottom of the list and I don't think that is fair.

Even though I am on that waiting list I have had no contact from the hospital at all. The surgeon, the day that he looked at my x-ray and diagnosed me, went down to his colleague and got me put on to the waiting list. That was nine or ten months ago. I have not heard anything to confirm that I am on a waiting list. I think the communication is poor. Better communication would help to give you a bit of satisfaction of knowing where you were and give you a bit of guidance for how to plan your life. I wouldn't mind how the information was provided, a phone call would be quite nice. I think that it would be great that if you had a problem and you don't need to go to the surgery you can ring up and the doctor can ring you back and can maybe sort it out without wasting every body's time going in for surgery. With a phone call you can sort a lot of things out in one go, rather than emails or text messages.

Being on a waiting list impacts on your whole life. When you get older it impacts on your plans that you may be making for retirement or that you might be making for family. It really isn't good for your whole mental and physical being to be on a waiting list for long periods. Unfortunately I cannot see how things are going to change unless the health service is really looked at properly. I am one of the lucky ones who can afford to get it done and has great support around me but I think of those people who maybe have no family who are on their own and can't afford to go.

Case Study 9 – 46 year old female, unable to work

My issue started off suddenly in April with what they thought was a TIA (transient ischemic attack) which is like a mini stroke. I was referred from A&E to the stroke clinic. The Consultant initially didn't think it was a stroke he felt there was something going on because of the way my body was reacting to things. He said he wanted to carry out different tests and one of them was to be an MRI brain scan.

I had other tests and scans done which came back clear and I finally got the MRI brain scan in August. I waited from April to August for the MRI. When the results came through it was confirmed that I had a stage 3 brain tumour and my condition is now classed as terminal.

When I was initially referred for the MRI I wasn't told how long I would be waiting. Every week while I was waiting the doctor would call me for some sort of test but he kept saying if we had the MRI scan we could see how things were going. I didn't feel particularly unwell while the tests were going on otherwise I might have pushed and went privately. I wasn't feeling too bad and had no indication at all that it was something as serious as it was. In the end I was waiting five months for just one scan.

Every week I thought when will I be getting word about this MRI scan? When I did get the word we were away in England. I got a phone call to come when we were away. I said that I was sorry that I was away at the minute and they said they would ring me in a few weeks to rearrange. I said no, I wanted to organise it then and there, I told them to organise it with me on the phone. If I hadn't have pushed, if I had agreed that it was okay to ring me in another few weeks it could have added more time to my wait.

I got the scan on the Thursday the 17th August. I then got a phone call on the Monday morning telling me that they wanted to make an appointment for me to see the Consultant as soon as possible. They made it for that Wednesday. When I went to the clinic we sat for an hour waiting to see the Consultant. I thought that things must be okay because they wouldn't have brought me in to a routine clinic and left me sitting in a waiting room for over an hour with everyone else if they were going to tell me that it was something really serious. When the Consultant came out to call me in he asked that my husband come in as well. I knew at that point that I was going to be told something quite serious.

I was shocked, I couldn't even speak I was that shocked when they told me. I remember when he started to tell me that they had found a growth and it was very serious and that he was very concerned. After that my mind went blank and I was so upset and couldn't take in any more. I sort of relied on my husband to ask the questions. We just didn't know what to do with ourselves; we didn't know what to ask. It wasn't what we were expecting to hear at all.

Unfortunately the Consultant couldn't convince the specialist hospital to take me on immediately as an urgent patient because the MRI scan hadn't been done with contrast. He

explained that he was very annoyed because I needed to be treated urgently. He put me back on the list for another MRI scan with contrast this time. The Consultant, now knowing it was a tumour, actually phoned the imaging department himself to get my MRI appointment brought forward. I don't know what stops he pulled out but I got the appointment the next day.

When the second MRI scan with contrast came back the team was able to confirm that it definitely was a tumour. I was then told to attend an appointment the following week and meet with the surgeon. I probably waited about a month from my diagnosis until surgery. I thought that it might have been faster but they had a lot of people in front of me and although I was a medical emergency they still had to do the pre-assessments and things like that. I was diagnosed on the 24th August and I didn't have the surgery until the 3rd October.

I would say that I am very disappointed in the wait for the MRI, not so much for the wait for surgery because during that period I was being informed about what was happening, they did keep me up to speed. After the surgery and after I was discharged from hospital I wasn't provided with much information. Then I was referred to an Oncologist, he has been very good with keeping me up to date with what was happening. Since my chemotherapy was stopped back in August, due to my fourth bout of sepsis, I have been left in limbo again where I don't know what is happening or when I am going to be called. I was told that I was probably to be seen every six months but to me I feel it should be every two or three months. I am maybe asking for too much.

My last MRI scan was in September and I didn't get the results of it for 10 weeks. For 10 weeks I was wondering whether the treatment had worked, whether anything was wrong or whether it was growing. I rang three times asking and was told that this was standard that I would have to wait for an appointment to see the Consultant. I told them that I knew that but I really wanted to know what was going on, that this was a stage 3 tumour and I wanted to know if the cancer had got worse, if the treatment that they had been giving me all year has helped. I know that the results were on their system and quite possibly if it had of been something serious I would have been called but it didn't help having to wait 10 weeks to be told.

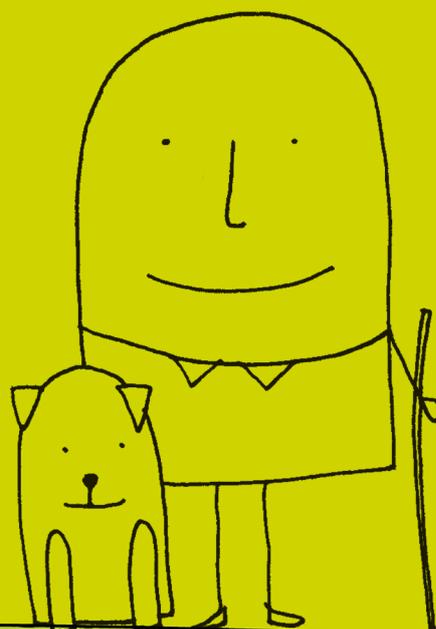
My diagnosis is terminal and I just thought the hospital would always keep in contact with regular checks, perhaps monthly. I wish they would have more contact with you to reassure you and tell you that you hadn't been forgotten about and would tell you that you were on their system. Let you know that they are there for you if you need them, if things become worse or your symptoms progress.

My mental health has not been good I have finally had to succumb to the anti-depressants. At the start I felt that I was going to beat this and I was going to be strong and determined but I could feel myself dipping and I knew I wasn't able to keep it up. I was putting a front on more for people than what I was actually feeling. I went in to my GP one day and chatted to him

and he said he would give me help because I needed to be in the right frame of mind. I have my children as well and I very quickly learnt that if I was feeling down about my diagnosis then everyone else around me would be feeling down. So I was trying to maintain this pretence that I was fine.

I think that the waiting times are ridiculous. When I was initially diagnosed I felt more annoyed about what they had found but then after time I was angry because they let me go from April to August with a brain tumour that was growing in my head causing more damage. I had no indication that it was something more serious. If they had even told me that it could have been something like a brain tumour I wouldn't have waited, I would have went privately. I still feel that A&E should have done some sort of a test, like a CT scan, that night and they would have seen that something wasn't quite right. Maybe they felt that it was only a TIA and were not in a hurry and felt I could wait on the MRI.

I do feel let down that I had to wait for so long. It will always be on my mind that if I hadn't had to wait for so long maybe my diagnosis would have been better. Maybe it wouldn't have been a terminal diagnosis maybe they would have been able to do something earlier but I will never know.

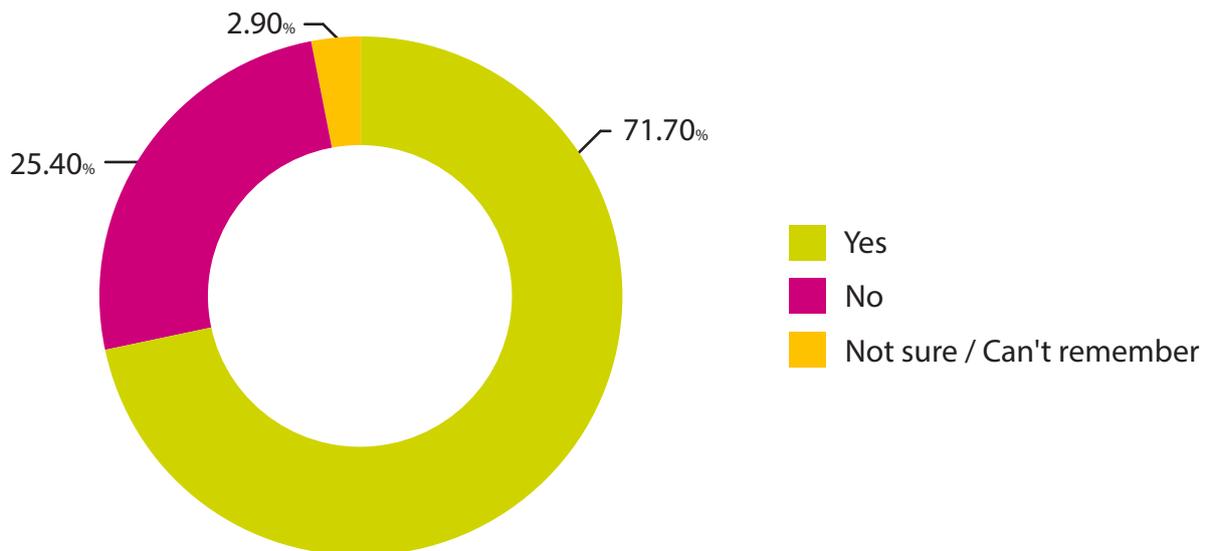


3.5 Information

3.5.1 Participants awareness of current waiting times

When asked, the majority of participants (N=494) said they were aware of the current situation with hospital waiting lists in Northern Ireland (i.e. that a significant proportion of people wait longer than the ministerial target). About a quarter of participants (N= 175) said they were not aware.

Figure 5: Participants' awareness of current waiting times



3.5.2 Information provision regarding waiting times

In contrast, there was mixed feedback from participants when they were asked if it had been explained to them how long they could expect to wait when they were first referred with 337 participants saying it hadn't been explained to them while 319 felt it had been explained.

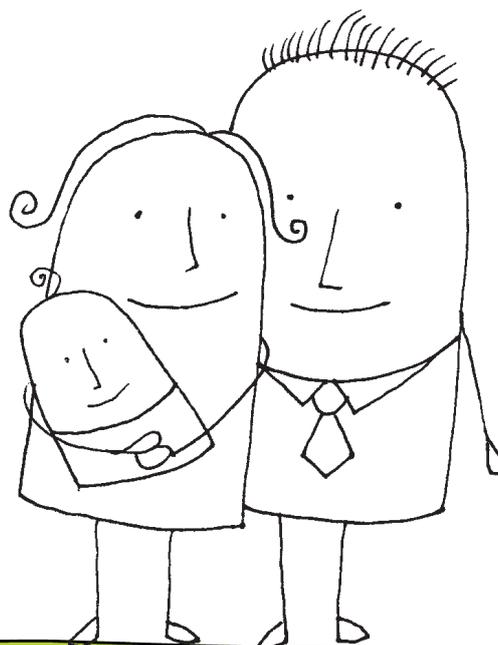
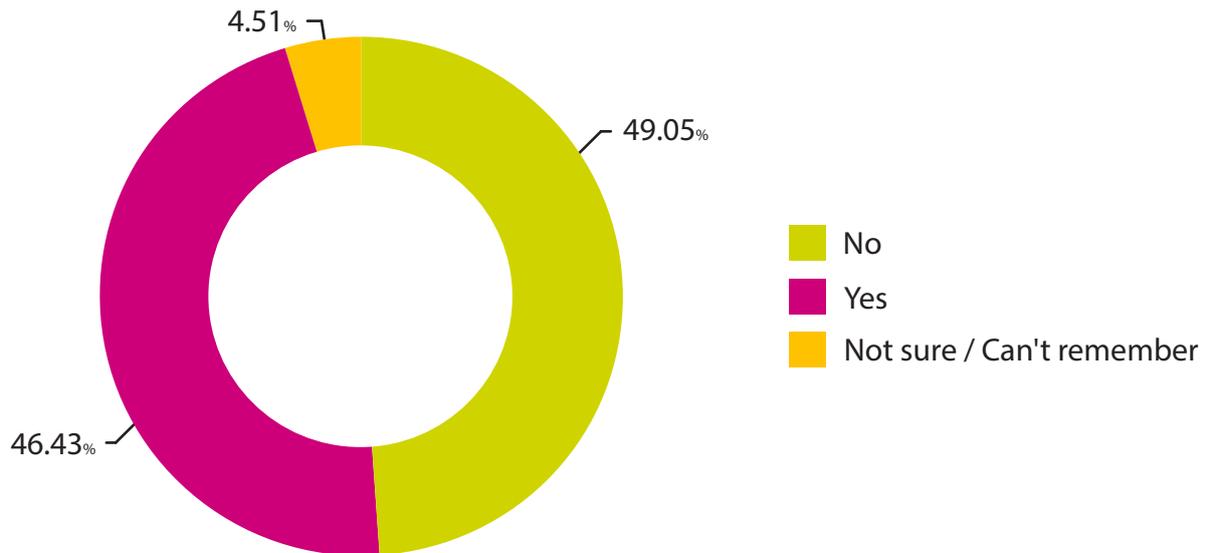


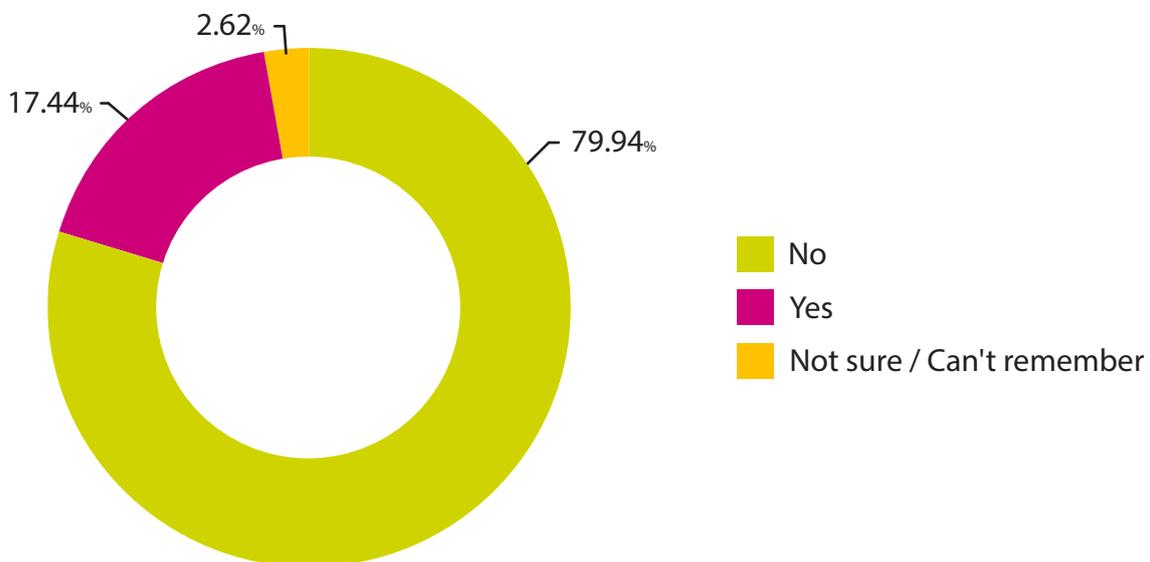
Figure 6: Was it explained to participants how long they could expect to wait?



3.5.3 Follow-up processes

Nearly 80% of people (N=550) said they were not followed up while they were on the waiting list to determine whether they still needed the appointment.

Figure 7: Were participants contacted to ask if they still needed their appointment?



3.5.4 Information provision regarding waiting list processes

Participants were also asked if they were made aware about what would happen if they could not attend an appointment (i.e. that they would have their waiting time adjusted to commence on the date they informed the HSC Trust they could not attend) or if they failed to attend an appointment (i.e. that they would have their waiting time adjusted to commence on the date they did not attend). Overall the majority of participants said they had not been provided with this information or that the information had been provided but was difficult to understand.

At any time were you given information about how your waiting time could be affected if you told the hospital you could not attend an appointment?	Number	%
No, no one provided any information on what would happen	395	58.43%
Yes but the information was difficult to understand	14	2.07%
Yes and the information was easy to understand	207	30.62%
Not sure / Can't remember	60	8.88%
Grand Total	676	100.00%

At any time were you given information about how your waiting time could be affected if you failed to attend an appointment without telling the hospital?	Number	%
No, no one provided any information on what would happen	371	54.96%
Yes but the information was difficult to understand	14	2.07%
Yes and the information was easy to understand	228	33.78%
Not sure / Can't remember	62	9.19%
Grand Total	675	100.00%

3.5.5 Is there a need for additional information to be provided to patients?

When asked, the majority of participants (N=497) stated that they would have liked to receive more information about being on a hospital list for example, more regular updates as to how long they could expect to wait. Approximately 20% (N=143) said they wouldn't have like more information and 5% (N=38) said they were unsure whether they wanted more information.

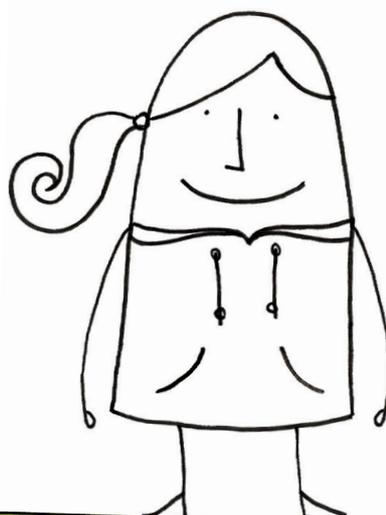
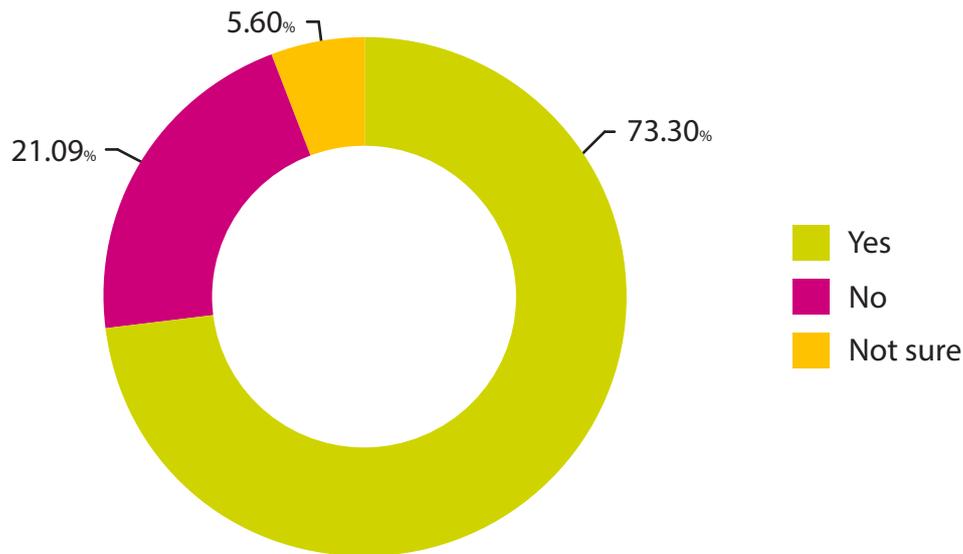


Figure 8: Would participants have liked more information about being on a waiting list?



Reasons participants gave for not wanting any additional information centred on the feeling that information wouldn't change the situation with waiting lists or that the resources required to provide information would stretch already limited services. In many cases those participants who said they would have liked more information provided further clarification as to what information would have been helpful.

"A text message once a month would be sufficient to keep patients updated on approximate timeframes. Patients should also be given the opportunity to attend any last minute cancelled appointments."

"An acknowledgement of receipt of my referral and an estimation of when I could expect to hear about an appointment."

"It is important to get updates and things explained as it eases the stress and anxiety if you know the appointment is coming up."

"Better communication as you move up the list would help. Sometimes you are waiting so long you think that you have been forgotten about or even that you may not actually have been referred."

"Lack of information is a really big problem. Unfortunately the people who do advise you about delays are just doing their job and have no other information other than tell you what they are told to tell."

"I rang the scheduler a few times, to see where I was on the list and how long I was expected to wait. Had I not have done this, I would not have been able to make plans regarding my university placements."

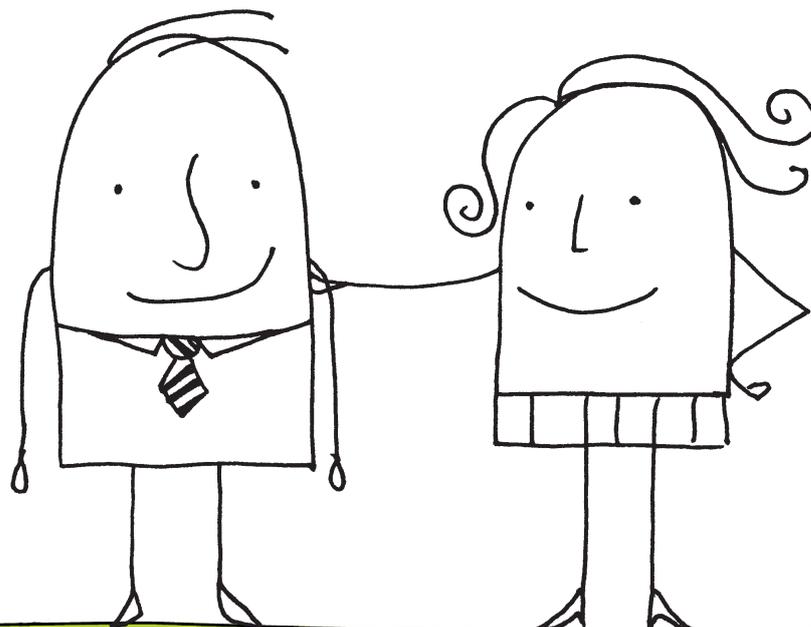
"The thing that annoyed me most is that I phoned every three months to enquire about how long it would be before I got an appointment only to be told the waiting time had been extended. In this day and age the Trust should have been contacting me to give me updates on waiting times either by electronic mail or texts."

"Might change people's attitudes to going private if they are made aware of length of time they might have to wait."

"I would like to receive appointment letters and test results in a format I can read, by e-mail would be easiest all round."

"The best way to manage expectations is to keep patient advised of on-going expectant time tables and to explore all avenues for possible interim solutions or remedies e.g. to maximise pain control."

"The unconscionable delays I have experienced in the Northern Ireland NHS have been vastly extended by its hopelessly obsolete and inefficient bureaucratic system. This virtually ignores the digital age and relies instead on dictated, typed and posted letters. These take a week to send and it takes a further week just to receive a reply - if you are lucky! Use of the telephone to speed up and introduce two-way communication into the process is frowned upon, apparently because there would be no audit trail. "



4.0 Discussion

The time patients wait for appointments and treatment is important to them. Studies have found that a patient's experience of their care is often dependent on the amount of time they have to wait from referral to treatment.¹⁶ Long waits for treatment and care can impact on the physical, emotional, and financial wellbeing of patients and their family and carers.¹⁷

One research study which looked at the impact of waiting for general surgery on health related quality of life concluded that, for many people, waiting for treatment involves a prolonged period of decreased health and affects the social and emotional life of the patient waiting.¹⁸ The study found that in each group of patients surveyed, the waiting period involved increased levels of anxiety and worse general health perceptions than after the surgery. Many patients also indicated that social activities and employment were negatively affected while they were waiting.¹⁸ A recent analysis paper on patient surveys on NHS waiting times in Wales also found that many people (around a third of those surveyed) felt that their health got worse as they waited for treatment.¹⁹

A number of reports have suggested that there may be a link between the information patients receive about waiting for treatment and care and their experience of waiting.^{16,18,19} Early information about how long a patient can expect to wait and notification of any delays can promote a patient's acceptance of waiting.^{18,19} Informing patients about their responsibilities around attending appointments can help them understand the impact of their own actions on the amount of time they will wait for treatment; for example letting the hospital know as soon as possible if they cannot attend and understanding what will happen if they fail to attend.¹⁶

The Patient's Association identified three key concerns patients have regarding waiting times. The communication issues between the Trust and patient's was a key concern for patients as they felt that the onus was on them to find out their surgery dates and waiting times. Psychological distress was another issue for patients waiting to be given a date. Finally patient safety, many patients worry that due to long waits their health will have deteriorated and that their surgery will not be as effective.²⁰

The information gathered by the PCC in this project clearly reinforces the key findings from previous research regarding the physical, emotional, social and financial impact on patients who are on a waiting list. In addition, our findings highlight concerns individuals in Northern Ireland have in relation to inequity in access to healthcare, that is particularly evident between those who are able to access private healthcare and those who are not; and, the waste of healthcare resources especially in relation to medication, burden on GP services and acute services while people remain on waiting lists. The majority of participants in this study also felt that the current approach to information provision around waiting lists is inefficient and inadequate and highlighted that communication processes need to be improved to enable the flow of accessible and accurate information.

5.0 Conclusion and actions

Patients are in crisis due to the waiting times for treatment in Northern Ireland. Waiting for treatment is a worrying and frustrating time for people who are unable to make decisions or plans while they are waiting. Life is on hold physically, financially and socially and many people will not return to their full health potential because the treatment they have been waiting on has been delayed for too long.

Through this study we heard from people who clearly needed access to better pain management while waiting for procedures, those who had fallen between the cracks when transitioning between services, and those who have been left wondering whether earlier intervention could have resulted in better prognosis and in some cases life expectancy.

Within the draft Programme for Government (PfG) (2016-2021) one of the outcomes is 'We enjoy long, healthy, active lives'. One aspect of this outcome is about 'ensuring that people get the right care, of excellent quality, at the time of need'. It is clear that the current situation with waiting times is counter strategic to the ambition outlined in the PfG.²¹

The waiting list crisis is the result of a combination of factors and urgent service modernisation and reform is required. An 10 year approach to transforming health and social care Health and Wellbeing 2026: Delivering Together, was launched in October 2016.²² The plan aims to radically reform the way services are designed and delivered. Part of the goal outlined within the document is that 'when care is needed, people will have access to safe, high quality care and are treated with dignity, respect and compassion. Staff will be empowered and supported to do what they do best while services will be efficient and sustainable for the future.'

One aspect of this reform is an 'Elective Care Plan', to address the issue of long waiting lists.¹³ The plan was published in February 2017 and work is ongoing to monitor progress but investment is required to take forward the commitments in the Plan. However, for many of the people we spoke to that reform is not going to happen quickly enough for them or their families. Nevertheless they were supportive of any improvement that would improve the existing situation.

Ensuring that waiting times are an ongoing item of importance on Trust Board agendas would seem advisable in order to promote action which can currently be taken to impact on the waiting list situation.

People who participated in this report identified a number of actions that could be taken immediately to address and improve the experience of those who are currently waiting. These included:

- ▶ Honest conversations about the length of time people will wait so they can make informed decisions about their care;
- ▶ Ongoing communication with people to keep them informed of their waiting status;
- ▶ Regular updating of waiting lists so that they are an accurate reflection of the situation, and
- ▶ Better use of technology to improve communication between patients and professionals and professional to professional.

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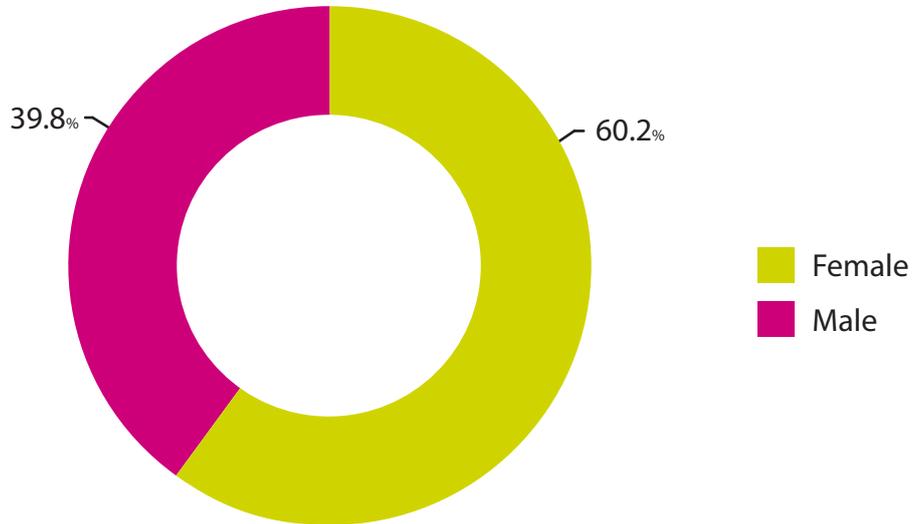
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Appendix 1: Profile of participants

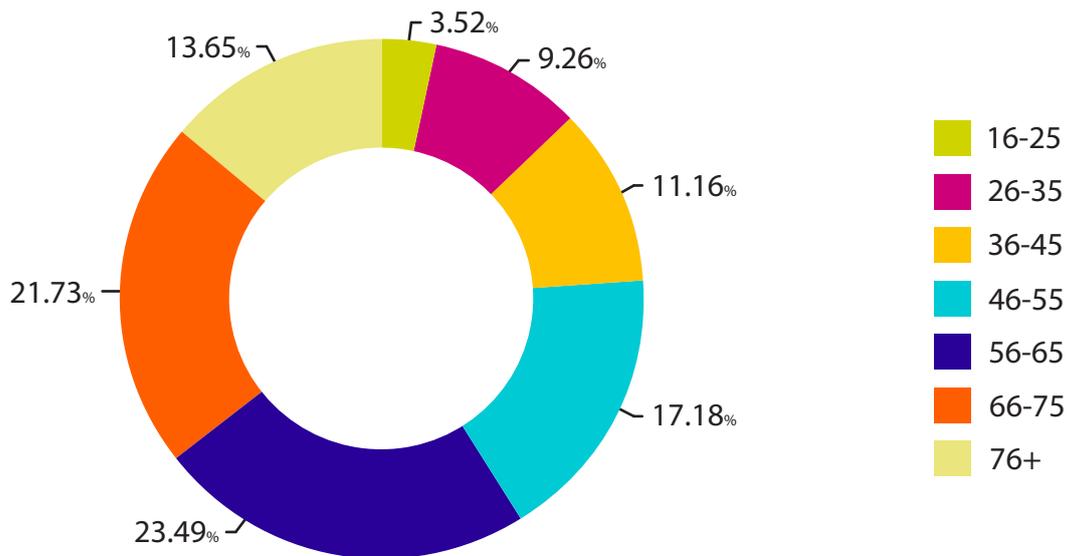
Approximately 60% (N=415) of participants were female and 40% (N=274) were male.

Figure A1: Gender of participants



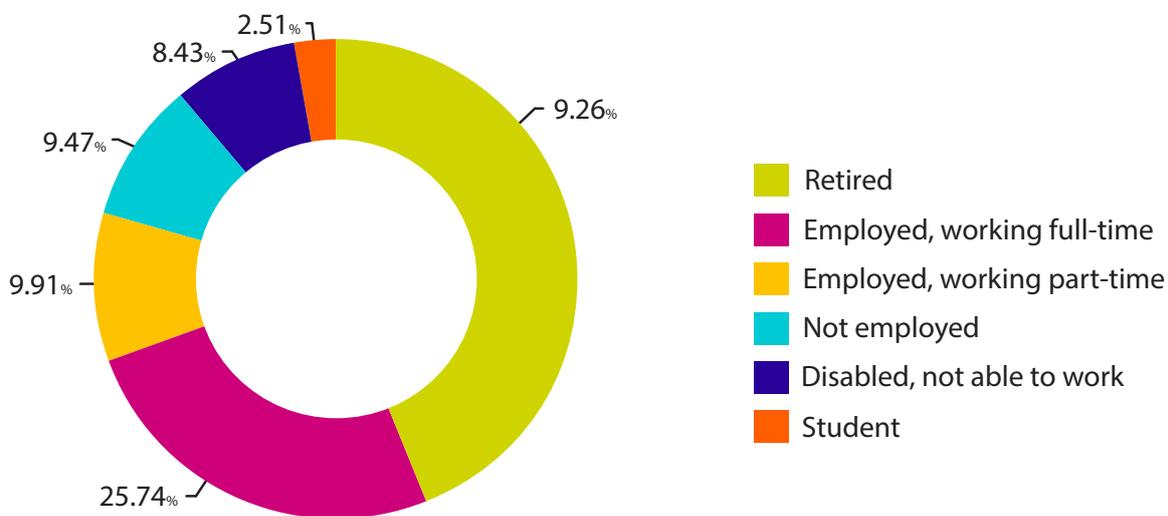
Individuals aged 56-75 accounted for approximately half of the total participants (56-65 years N=160; 66-75 years N=148). Younger participants, those aged under 35, accounted for less than 15% of participants (N=87).

Figure A2: Age of participants



Over 40% of participants were retired (N=297/676) while approximately 35% were in employment (Full time employment N=174; Part time employment N=67). The remaining participants identified themselves as 'not employed (N=64), 'disabled and not able to work' (N=57) or as a 'student' (N=17).

Figure A3: Employment status of participants



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